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# Patient Reactions to a Program Designed to Facilitate Patient Participation in Treatment Decision for Benign Prostatic Hyperplasia

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## Patient Reactions to a Program Designed to Facilitate Patient Participation in Treatment Decisions for Benign Prostatic Hyperplasia

MICHAEL J. BARRY, MD,\* FLOYD J. FOWLER, JR., PHD,† ALBERT G. MULLEY, JR., MD, MPP,\* JOSEPH V. HENDERSON, JR., MD, MA,‡ AND JOHN E. WENBERG, MD§

**Patients often want considerable information about their conditions, and enhanced patient participation might reduce unwanted practice variation and improve medical decisions. The authors assessed how men with benign prostatic hyperplasia reacted to an educational program designed to facilitate participation in decisionmaking, and how strongly ratings of their symptom state and the prospect of complications predicted their treatment choice. A prospective cohort study was conducted in three hospital-based urology practices: two in prepaid group practices, and one Veterans Administration clinic. Four hundred twenty-one men with symptomatic benign prostatic hyperplasia without prior prostatectomy or benign prostatic hyperplasia complications were enrolled, and 373 provided usable ratings. Subjects participated in an interactive videodisc-based decisionmaking program about benign prostatic hyperplasia and its treatment options, prostatectomy, and "watchful waiting." They rated the length, clarity, balance, and value of the program and were followed for 3 months to determine if they underwent surgery. Patients rated the program as generally clear, informative, and balanced. Across all three sites, 77% of patients were very positive and 16% were generally positive about the program's usefulness in making a treatment decision. Logistic models predicting choice of surgical treatment documented the independent importance of negative ratings of the current symptom state (odds ratio 7.0, 95% confidence interval 2.9-16.6), as well as the prospect of postoperative sexual dysfunction (odds ratio 0.20, 95% confidence interval 0.08-0.48) in decisionmaking. Patients rated the Shared Decisionmaking Program very positively and made decisions consistent with their assessed preferences. These results suggest that patients can be helped to participate in treatment decisions, and support a randomized trial of the Shared Decisionmaking Program. Key words: benign prostatic hypertrophy; prostatectomy; patient education; patient participation; videodisc. (Med Care 1995;33:771-782)**

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For many medical conditions, multiple treatment options are available. In many of these situations, decisions about optimal treatment for an individual patient should depend on that patient's values for, or preferences about, his or her current medical state, as well as for the outcome states possible after each of the treatments.<sup>1</sup> When an optimal decision is heavily dependent on these personal values, it is especially important to involve the patient in the decision-making process.<sup>2</sup> Men facing the choice between prostatectomy and "watchful waiting" for benign prostatic hyperplasia (BPH) face this type of decision; they must weigh the small risks of surgical death, incontinence, and impotence, against a large expected improvement in symptoms after surgery.<sup>3,4</sup>

Communicating the elements of a complex medical decision to patients, including the risks of all relevant outcomes and the nature of those outcomes, is difficult and time consuming. We designed an interactive media program (both computer- and videodisc-based) to communicate information bearing on the choice of treatment for symptomatic BPH. The Shared Decisionmaking Program (SDP) presented the treatment options then available, prostatectomy, and watchful waiting, and elucidated the risks and benefits of the two alternative strategies. The interactive nature of the SDP allowed presented probabilities to be tailored to patients' specific characteristics. Moreover, patients were given "vicarious experience" with potential outcome states through presentations from previous BPH patients. Because there is great controversy about the way probabilities and utilities should be synthesized to reach an optimal decision for an individual patient,<sup>5,6</sup> the program did not prescribe one of the treatment options, but left the final decision to the patient and his physician.

In this report, we describe the reactions of a consecutively enrolled group of BPH patients into whose care the program was integrated. We also examine the treatment choices of these men to determine whether their assess-

ments of the value of possible outcomes were indeed predictive of their decisions.

Because the program presents a large amount of information that might be confusing, because elderly men might not successfully interact with computers, and because research has suggested that some patients are uncomfortable with increased participation in medical decisionmaking,<sup>7-9</sup> we felt an evaluation of patient response to the SDP was a prerequisite for further dissemination of the SDP and a controlled trial of its impact on patient decisionmaking.

## Methods

### Design of the Shared Decisionmaking Program

The SDP was designed to be shown to patients who were diagnosed as having symptomatic BPH after an office evaluation. Patients were introduced to the concept by their urologists, and given an introductory brochure. Patients also completed a questionnaire, providing information on demographics, symptoms, and health status. A subset of these variables was used to configure the program to the patient's characteristics (age, self-rated general health, history of acute retention, and symptom level). Patients were scheduled for a visit to view the program, where a nurse entered questionnaire data and oriented them to the computer and mouse input device.

A Macintosh II computer (Apple Computer, Inc., Cupertino, CA)—was used with a video overlay card, color monitor, and a laser disc player to present the program. The software for this version of the program was a combination of HyperCard 1.0 (Apple Computer Inc., Cupertino, CA)—with specially developed external commands written in C and Pascal—and Videoworks II (Macromedia, Inc., San Francisco, CA).

The SDP synthesized motion video, audio, and real-time computer graphics (still and animated) to present information to the viewer. All patients saw a 22-minute "core"

segment that outlined the basic choices of prostatectomy and watchful waiting, and listed the possible harms and benefits of each treatment along with the probabilities of these outcomes. Probabilities were communicated both verbally and graphically, with attention paid to issues of framing<sup>10,11</sup>; for example, probabilities of both perioperative death *and* survival were presented. During this segment, the viewer was introduced to two physician-patients who had chosen different treatments for their BPH condition and were satisfied with their choices.

After the core segment, the viewer entered a more interactive "elective" segment that allowed for both review of old material and presentation of new material. The viewer could choose individual optional modules from a central screen. Three of these modules provided more in-depth information on acute retention, sexual dysfunction, and incontinence, including descriptions of these problems from actual patients. There were also modules describing the way a transurethral prostatectomy is performed, the relationship between BPH and prostate cancer, and the use of blood products in surgery. Patients could also explore a module to find out how an individual symptom that may have been particularly troublesome was likely to respond to transurethral prostatectomy. Finally, a module contained information about many emerging treatments just beginning to be used for BPH at the time of the study,<sup>12</sup> including balloon dilation, transurethral incision of the prostate, and drug treatment with alpha-adrenergic blockers or hormonal manipulation. These segments contained a total of 25 minutes of additional material. A printed summary of the information provided in the program was generated for the patient and his urologist.

### **Information Communicated in the Shared Decisionmaking Program**

The development of the didactic content of the program was an extension of the effort of a multi-institutional Patient Outcome

Research Team for prostatic diseases.<sup>13</sup> Probabilities used in the group's decision analysis on treatment of moderately symptomatic BPH were used in the program<sup>3</sup>; in turn, these probabilities were derived from the medical literature as well as both retrospective, claims-based and prospective cohort studies of the outcomes of prostatectomy.<sup>14-16</sup> The derivation of the probabilities cited in the program are discussed in detail in these articles. For example, the risk of erectile dysfunction after surgery was cited to sexually active patients as 5% on a consistent basis, and 21% on an intermittent basis, based on face-to-face structured interviews preoperatively and 3, 6, and 12 months postoperatively with 263 patients who underwent prostatectomy in Maine in the years 1983 and 1984.<sup>16</sup> Team members with expertise in education, informed consent, and medical ethics also helped design the program.<sup>17</sup> Video material presented in the form of patient interviews was selected to ensure that segments optimally conveyed the desired concepts and did not unbalance the program in favor of one treatment strategy.

After extensive pretesting for clarity and balance, the final program was integrated into the care process in three urologic practices: the urology clinic at the White River Junction Veteran's Administration Hospital in Vermont (2 urologists), the urology practice of the Kaiser Permanente Medical Care Program in Denver (5 urologists), and the urology practice of the Tacoma region of Group Health Cooperative of Puget Sound (3 urologists).

Individual patients were eligible if they were referred to the practice with urinary symptoms that, after investigation, were believed by the participating urologist to be due to BPH. Exclusion criteria for the study are listed in Table 1. Basically, patients with suspected prostate cancer, or requiring surgery to reverse or prevent incipient bladder or renal decompensation were not eligible. In addition, patients who had a prior prostatectomy were excluded, because the

TABLE 1. Exclusion Criteria

Clinical suspicion of prostate cancer
Evidence of obstructive uropathy (eg, elevated creatinine; hydronephrosis or hydronephrosis)
Evidence of severe bladder decompensation (eg, residual urine volume of >350 mL on 2 determinations)
Repeated or intractable urinary tract infections
Repeated or intractable acute retention
Prior prostate surgery
Not a candidate for prostatectomy due to poor general health
Unable to understand spoken English

probabilities presented in the program were derived from first operations. All subjects provided written, informed consent.

### Patient Reactions to the Shared Decisionmaking Program Experience

After patients had seen the program, they provided on-screen ratings of their reactions with respect to its length, clarity, and balance. They were also asked to rate how they felt about patients seeing the SDP before a treatment decision was made.

Patient ratings are presented as simple distributions. Analyses of  $n \times n$  tables examining the effect of education on responses, as well as analyses of baseline characteristics by site, were performed using the chi-square statistic.

### Predicting Patients' Treatment Choices

In the baseline questionnaire, patients provided demographic information and reported the frequency of their urinary symptoms. Objective data on their urologic condition was abstracted from urologic office records. Patient responses to five questions about their symptoms were translated into a symptom frequency score, with a range of 5 to 25 points (Table 2). This index has been previously demonstrated to be internally consistent and sensitive to clinically impor-

tant changes. The symptom scores can be categorized as mild (5–8 points), moderate (9–12 points), or severe (13 or more points).<sup>16</sup>

Patients also rated how they felt about their current symptom state, and how they thought they would feel about experiencing three common postprostatectomy complications: retrograde ejaculation, erectile dysfunction, and incontinence. The four questions and the common response frame are also provided in Table 2. Unlike some utility measurement methods, such as the basic reference gamble,<sup>18</sup> these category scaling tasks do not incorporate an assessment of patient attitude toward risk. Rather, they are based on a rating task previously found to be better than many competitors for describing

TABLE 2. Symptom and Value Questions

#### Symptom questions

Over the past month or so, how often have you:

1. Had a burning feeling when you urinate?
2. Had to push or strain to begin urination?
3. Had to urinate again shortly after you were finished urinating?
4. Found you stopped and started again several times when you urinated?
5. Dribbled urine after you thought you were finished urinating?

Ordered categorical responses: (1) not at all, (2) a few times, (3) fairly often, (4) usually, (5) always

#### Value questions

1. Suppose your urinary symptoms stayed just the same as they are now for the rest of your life. How would you feel about that?
2. Suppose a treatment cured your urinary symptoms, but after the treatment any sexual climaxes would result in retrograde ejaculation. How would you feel about your situation?
3. Suppose a treatment cured your urinary symptoms, but you were not able to have sexual erections. How would you feel about your situation?
4. Suppose a treatment cured your urinary symptoms, but you occasionally dripped urine or wet your pants slightly. How would you feel about your situation?

Ordered categorical responses: (1) delighted, (2) pleased, (3) mostly satisfied, (4) mixed, (5) mostly dissatisfied, (6) unhappy, (7) terrible

subjective evaluations of a wide range of situations and events.<sup>19</sup>

In practical terms, the decisionmaking process continued after the interaction with the SDP, with the patient often consulting both family members and his urologist before making a treatment decision. Patients choosing surgery also often faced a short scheduling delay. For the purposes of these analyses, all patients who underwent a prostatectomy within 3 months of their SDP visit were defined as having surgery as their treatment of choice.

Univariate relationships between the outcome of interest, choosing surgery as opposed to watchful waiting, and dichotomous potential indicator variables were explored if  $2 \times 2$  tables, and the significance of the relationships tested with the chi-square statistic, as well as calculation of test-based confidence intervals (CI) around the point estimates of the odds ratios (OR).<sup>20</sup> Relationships between dichotomous variables and ordered categorical variables were evaluated with the chi-square test for trend. Relationships between continuous indicator variables were examined using Pearson product-moment coefficients, and between categorical variables using phi coefficients.<sup>21</sup> To determine independent predictors of the choice of surgery, logistic regression models were constructed using the log odds of choosing surgery as the dependent variable, and potential indicator variables as independent variables. Given the relatively small percentage of patients choosing surgery, no more than four indicator variables were included in any of the logistic models, maintaining a ratio of at least five patients (closer to 10) with outcome "events" (surgery) for each independent variable.<sup>22</sup>

## Results

Between June 1989 and December 1990, 421 patients viewed the SDP at the three sites. Patients were willing to make the extra visit to participate. Although participating

sites did not keep logs of all eligible patients who were presented the viewing option, each site estimated that more than 80% of eligible patients returned to watch the program.

While completed baseline questionnaires were available for 403 of the 421 subjects (96%), because of some initial problems with the software and data retrieval systems, patients' on-screen ratings of the SDP experience and possible outcome states were available for 89% (373 of 421) of the subjects. There were no statistically significant differences with respect to age, educational level, symptom level, or pre-SDP treatment preferences between those with and without SDP ratings.

Across all sites, 78% of patients were aged 60 years age or older; 27% were 70 years or older. Educationally, 23% had not completed high school, and 45% had attended college. Symptoms were mild in 28%, moderate in 51%, and severe in 21%. Self-rated health was excellent or very good in 44%, good in 34%, and fair or poor in 22%. Twenty-four men (6%) had experienced an episode of acute urinary retention. A total of 225 men (56%) reported they were able to have erections at least fairly often when sexually stimulated; only 15% reported no erections in the previous year. Forty-three patients (10.7%) ultimately underwent a prostatectomy within 3 months of interacting with the educational program.

The urologic evaluation of patients differed depending on their urologist, the practice site, and patients' clinical characteristics. Across all sites, 17% had a uroflow study, 59% underwent cystoscopy, and 25% had an imaging study of the upper urinary tract. Altogether, 239 patients (59%) had a determination of post-void residual bladder volume by some method (intravenous pyelography, ultrasound, or catheterization). Of these men, 62% had a post-void residual bladder volume less than 100 mL, 25% had 100 mL to 199 mL, 6% had 200 mL to 299 mL, and another 6% had 300 mL or more.

The patients at the three sites were not significantly different with respect to age or symptom scores. However, the VA patients were significantly less likely to have attended college than the patients at the health maintenance organization sites ( $P < 0.01$ ).

### Patient Reactions to the Shared Decisionmaking Program Experience

Table 3 presents the four basic ratings of the program obtained from study patients. Although attributing absolute meaning to ordinal ratings is inappropriate, the SDP did not appear to contain too much information for most patients. Eighty-seven percent rated the amount of information to be about right, and six percent more said they would have liked more information. The ratings of program length were equally positive; only 5% rated the program "a little too long." In addition, 99% said that either "everything" or "most things" were clear, which is encouraging evidence that most patients felt comfortable with their understanding of the information presented.

The issue of balance was critical to the underlying concept of the SDP; the goal was to present both options in a way that favored neither. During the developmental phase, patients and physicians rated iterative revisions of the program for balance, and discussions were held to identify parts of the program that might be inappropriately biased toward one treatment.

The ratings in Table 3 suggest success in achieving a perception of balance among viewers. Seventy-four percent thought the program was completely balanced, and the dissenters differed in which direction they believed it was slanted. Overall, there were more raters who thought the SDP favored waiting than surgery. Interestingly, patients who rated the program slanted in one direction had a very strong tendency to think it was slanted in the direction in which they themselves were leaning according to their

TABLE 3. Patient Ratings of the Shared Decisionmaking Program (n = 373)

	Percent
Amount of information	
Much less than wanted	1
Little less than wanted	5
About right	87
Little more than wanted	4
Much more than wanted	3
Length	
Much too long	0
Little too long	5
About right	92
Should have been a little longer	3
Should have been much longer	0
Clarity	
Everything clear	63
Most things clear	36
Some things unclear	1
Many things unclear	0
Balance	
Clearly slanted to surgery	1
Slightly slanted to surgery	7
Completely balanced	74
Slightly slanted to waiting	14
Clearly slanted to waiting	4

answers on the postprogram questionnaire. Of those leaning toward surgery who thought the video was not completely balanced, 77% rated it slanted toward surgery. Of those leaning toward waiting who stated that it was not completely balanced, 82% felt it was slanted toward waiting. These findings illustrate the difficulty of separating true "balance" of the SDP presentation from the perceptual frameworks of the viewers.

Table 4 shows that patients who had not finished high school were significantly more likely than others to feel there was more information in the program than they wanted. Those who attended college were significantly more likely than others to say that "everything" was clear in the program. Nonetheless, in all educational categories,



TABLE 4. Selected Ratings of Interactive Video by Patient Education

	Less Than High School (n = 85)	High School Graduate (n = 119)	College (n = 167)	P
Amount of information (n = 371)				
Less than wanted	6	5	7	
About right	78	93	87	<0.01
More than wanted	16	2	6	
Clarity (n = 371)				
Everything clear	54	57	71	<0.01
Most things clear	44	43	27	
Some/many things unclear	2	0	2	
Summary rating (n = 373)				
	(n = 86)	(n = 119)	(n = 168)	
Very positive	69	80	78	
Generally positive	24	13	15	0.26
Neutral	6	7	6	
Somewhat negative	2	0	1	
Very negative	0	0	1	

Note: Values are percentages. N values vary slightly due to individual item nonresponse.

the majority of patients thought everything was clear and fewer than 20% wanted less information.

Table 4 also presents the results of the summary rating: "In general, how do you feel about patients seeing a presentation like this before deciding whether or not to have prostate surgery?" The ratings were quite positive. Overall, 77% chose "very positive" as their response, and another 16% chose "generally positive." While patients who did not finish high school tended to give lower ratings, the differences were not statistically significant, and their overall ratings were still quite positive.

### Predicting Patients' Treatment Choices

Table 5 presents the relationships between choosing surgery and three indicator variables significantly associated with this choice. Using men with moderate symptoms as the comparison group, the odds of choosing surgery for men with mild rather than moderate symptoms were much lower (OR

0.08, 95% CI 0.02–0.4), and higher for men with severe compared to moderate symptoms (OR 2.4, 95% CI 1.2–4.6). The probability of choosing surgery also increased when men rated their current symptoms negatively. Men who assigned positive ratings to remaining in their current symptom state (ratings of delighted, pleased, or mostly satisfied), or who were ambivalent (mixed) had virtually the same low probability of choosing surgery, 4.8% and 4.9%, respectively. Men who were negative about the prospect of remaining in their current symptom state (ratings of mostly dissatisfied, unhappy, or terrible) had relative odds of 8.4 (95% CI 4.2–16.6) of undergoing surgery compared to men in the other two categories.

Finally, a similar proportion of patients who were not bothered by the prospect of postsurgical impotence and men who were ambivalent about impotence underwent surgery, (18% and 13%, respectively). The relative odds of choosing surgery for men with negative ratings of the prospect of im-

TABLE 5. Univariate Predictors of Choosing Prostatectomy

Variable	Proportion Electing Surgery	OR	95% CI
Symptom score <sup>a</sup>			
Mild	1/107 (0.9%)	0.08	0.02, 0.4
Moderate	22/209 (10.5%)	—	—
Severe	19/87 (21.8%)	2.4	1.2, 4.6
Rating of symptoms <sup>b</sup>			
Positive/mixed	14/288 (4.9%)	—	—
Negative	18/60 (30%)	8.4	4.2, 16.6
Rating of impotence <sup>b</sup>			
Positive/mixed	20/135 (14.8%)	—	—
Negative	12/212 (5.7%)	0.35	0.17, 0.71

OR, odds ratio; CI, confidence interval.

<sup>a</sup>n = 403 because symptom scores were taken from the prevideo baseline written questionnaires, rather than the on-line ratings.

<sup>b</sup>n = 347–348 due to individual item nonresponse among the 373 patients completing the on-line postvideo questionnaire.

potence were 0.35, (95% CI 0.17–0.71) compared to men who were not bothered or ambivalent. Not surprisingly, ratings of the prospect of postoperative sexual dysfunction were more negative for men with less sexual dysfunction at baseline. For men who were seldom, usually, and almost always able to get erections at baseline, 47%, 56%, and 75% provided a negative rating of postoperative impotence, respectively (*P* < 0.001; chi square test for trend).

Age, education, marital status, and patient ratings of the value of symptom relief with either retrograde ejaculation or incontinence were not associated with the choice of surgery. Among the 239 men with a determination of post-void residual volume, there was no association of the post-void residual bladder volume with whether patients underwent surgery. Similarly, prior acute retention was not predictive of surgery.

The data given in Table 5 lead to questions about the independence of the predictors of choice of surgery. Certainly, a correlation would be expected between the frequency of a patient's symptoms and the degree to which those symptoms occur. However, consistent with our previous findings,<sup>16</sup> the correlation

coefficient between patients' symptom scores and symptom state ratings is only 0.34. Given that these two variables are relatively weakly correlated, major problems due to multicollinearity would not be expected when both are used as indicator variables in multivariable predictive models.

TABLE 6. Independent Multivariate Predictors of Choosing Prostatectomy (Logistic Regression; n = 347 Men With Complete Data on All Predictors<sup>a</sup>)

Variable	OR	95% CI
Symptom score		
Mild	0.09	0.01, 0.72
Moderate		
Severe	1.48	0.6, 3.6
Rating of symptoms		
Positive/mixed		
Negative	7.0	2.9, 16.6
Rating of impotence		
Positive/mixed		
Negative	0.20	0.08, 0.48

OR, odds ratio; CI, confidence interval.

<sup>a</sup>Thirty-two of these men underwent a prostatectomy.

Table 6 presents the results of a logistic regression model using the indicator variables as categorized in Table 5 to predict choice of surgery. Because of some heterogeneity in the proportion of patients undergoing surgery at the three sites, this model also controls for site as a covariate. This analysis is based on 347 patients with complete data for all indicator variables, of whom 32 underwent surgery within 3 months of interacting with the SDP. The relative odds of undergoing surgery comparing men with mild versus moderate symptoms are low (OR 0.09; 95% CI 0.01–0.72). In contrast, the relative odds of undergoing surgery with severe versus moderate symptoms were not significantly elevated (OR 1.48; 95% CI 0.6–3.6). Negative ratings of remaining in the current symptom state compared to positive or mixed ratings remained a strong independent predictor of choosing surgery (OR 7.0; 95% CI 2.9–16.6). Patient ratings of the prospect of postoperative sexual dysfunction also remained an important negative predictor of undergoing surgery (OR 0.20; 95% CI 0.08–0.48). No two-way interaction terms were significant. Overall, the model including site and these three variables was strongly predictive, with an overall chi-square of 49.3 ( $P < 0.001$ ).

To confirm the dominance of patients' feelings about their symptoms over symptom scores alone in predicting treatment choice for men with symptoms in the moderate and severe range (249 of the 347 subjects in Table 6), separate logistic models were constructed for this subset. Symptom scores, whether analyzed as a categorical variable using different moderate-severe cutpoints, or as a continuous variable, never reached statistical significance as a predictor of choosing surgery. In contrast, patient ratings of the bothersomeness of their symptoms and of the prospect of postoperative impotence remained powerful and significant predictors in all models examined.

## Discussion

Our pilot experience with the SDP for BPH suggests that patients are enthusiastic about being educated about their condition before an important treatment decision is made; these findings are consistent with the results of previous research.<sup>7,8,23</sup> Patients did not find the amount of information overwhelming, and, although we do not know the exact proportion, most were willing to return for an extra visit to see the SDP.

While previous research has supported the desire of patients to be informed, studies have also suggested that patients are less willing to participate in the decisionmaking process.<sup>7,8</sup> This observation has also been documented for physicians imagining themselves in a patient role.<sup>9</sup> However, patients, even physician-patients, may need to be educated about the importance of their relative preferences for outcome states in a particular decisionmaking scenario before they understand the appropriateness and importance of participating in the decision. While our study did not objectively document that subjects became more willing to participate in decision making, our participating urologists believed subjectively that they indeed became more active partners in the decisionmaking process.

In this cohort of well-informed patients, knowledge of symptom frequencies alone was insufficient to explain which patients chose surgical treatment for their BPH condition. In fact, for the subset with frequent moderate and severe symptoms, patients' ratings of the bothersomeness of their symptoms and their attitudes toward the prospect of postoperative sexual dysfunction were clearly the dominant predictors of choosing surgery. These findings are consistent with our prior decision analysis for men with moderate symptoms, which suggested that patient attitudes toward their symptoms and toward the prospect of postsurgical sexual dysfunction should drive decisionmaking for elective prostatectomy.<sup>3</sup>

They are also consistent with the work of Krumins and colleagues, who found in a study of 20 VA clinic patients that both symptom levels and expected utility gain from surgery were independently related to whether a prostatectomy was scheduled.<sup>24</sup>

Several limitations of our study must be acknowledged. While patients had favorable impressions of the program's clarity and content, we did not test for recall of the facts presented. The level of comprehension necessary to participate in making an informed treatment decision is unclear.<sup>25</sup> However, our brochure and printout of patient-specific outcome information were designed to make treatment decisions less dependent on a one-time interaction, and less vulnerable to limits of memory. While it seems unlikely that the missing ratings data from 11% of subjects would change the conclusions of our study if known, these missing data are a potential concern.

While we studied responses to the program in three different sites, reactions may be different elsewhere, particularly for patients with different social and cultural backgrounds. Our subjects were also relatively well educated. While the subgroup of patients with less than a high school education rated the program as valuable as those subjects with more education, a sample of patients with little or no high school education might have revealed that they responded less favorably. It may also be important that all our participating urologists were salaried and had no direct financial stake in whether patients chose surgery. This factor may have influenced the enthusiasm with which patients were presented the program and the concept of shared decision-making. Further testing in other settings is clearly necessary.

As indicated in Table 5, many patients who rate their current symptoms negatively still do not choose to undergo prostatectomy. In fact, of patients with severe symptoms and negative ratings of this symptom state, only 38% underwent surgery, at least

during the 3 months after viewing the SDP. Future studies should identify other variables that better explain this variation in treatment choice, particularly given the large implications that these decisions have on health care costs. For example, the category scaling task we employed to have patients express their attitudes about their symptoms and postoperative complications is not risk-based. That is, patients do not have to accept a risk of death or trade off a portion of future life expectancy, as they must with risk-based utility measures. Knowledge of patient attitudes about risk might allow even better prediction of treatment choice. Similarly, knowledge of patients' time preferences may improve prediction. Some patients value near-term years of life greater than years of life off in the future. Such patients are less likely to opt for surgery, with its near-term risks of morbidity and mortality, in exchange for future years with fewer symptoms.

In this study, patients were given a detailed presentation designed to fully educate them about their condition and encourage their participation in decisionmaking. Our study does not have a control group, so we cannot determine to what extent this preparation was responsible for our findings about predictors of treatment choice. The wide variations observed in prostatectomy rates suggest that in some geographic areas, decisionmaking relies less on patient preferences than was evident in this cohort, but this hypothesis remains to be proven. We also acknowledge that much of the data that support the facts in the SDP are of poor quality. Additional outcomes research is needed to improve the scientific basis of BPH treatment, including the conduct of randomized controlled trials.

One concern about allowing patients a greater role in decisionmaking is that some patients may be bothered enough by relatively mild symptoms that they might demand a costly treatment unreasonably. In fact, only 1 of 107 men with a symptom

score in the mild range underwent surgery. He actually indicated he was positive about remaining in his current symptom state, and underwent a prostatectomy largely on the basis of "objective" indications, including a post-void residual volume of 350 mL. The role of such objective indicators of urologic severity of BPH in therapeutic decisionmaking is controversial,<sup>26</sup> and needs further definition.

Our findings have implications for the development and implementation of practice guidelines for the treatment of BPH and other preference-driven medical decisions. Our results suggest that a reasonable two-tiered practice guideline for prostatectomy might be considered: avoid surgery for men with mild symptoms, and allow informed patient preferences to direct treatment choice for men with moderate and severe symptoms. Guidelines for preference-driven problems like BPH need to be written in ways that preserve the physician's ability to negotiate a treatment choice with individual patients, and implemented in a way that facilitates a shared decisionmaking model between physicians and patients. In fact, BPH guidelines that are in agreement with these principles have just been released by a panel supported by the Agency for Health Care Policy and Research.<sup>27</sup> The SDP may prove to be a practical method for helping to implement such guidelines in practice.

Based on favorable patient reactions to the SDP for BPH, we are expanding the use of the program to other sites. Long-term follow-up of patients who interact with the SDP should provide valuable outcome data that can be folded into future editions of the program. In addition, a randomized trial is underway studying the impact of the SDP compared to the usual process of decisionmaking for BPH. The trial will test a revised version of the SDP that incorporates new data from recent outcomes studies, and presents multiple treatment options (prostatectomy, transurethral incision, balloon dilation, drug treatment, and watchful waiting).

Given the phenomenon of moving technology in BPH treatment, frequent revisions of the program will likely continue to be necessary.

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